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Analyzing Dementia in Literature from the Perspective of Demented Selves and Caregivers with Special Study to Ranjit Lal, Kate Swaffer and Lisa Genova

A Comprehensive Report / Research Plan

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Introduction/ Importance of proposed Research

This work is important because of the dearth of research that exists with regards to dementia in literature world-wide. There is very less research that has been done in this area in Indian and other developing countries context, thus many peculiarities of society that are unique to India have not been taken into account by researchers so far. The importance of this research is further highlighted by the fact that the literature surrounding dementia is central to the paper that has been written by the writers world-wide. By linking abstract theories about dementia with relatable fiction, the researcher tries to distil dementia as a very understandable problem, this would make the theories much more lucid for the layman. Another benefit of using fiction as a tool to understand dementia is that by making dementia a human problem, the stigma around dementia would reduce, as goes with mental illnesses, the more one talks about dementia and diseases the more the stigma would reduce.

This research answers the three basic assumptions:

- How does one contextualize dementia as an illness in the context of society and in literature?
- What are the factors that are involved in handling dementia vis a vis the patient, the family and friends of the patient and the larger society as a whole?
- In understanding a concept, it becomes a very effective exercise to apply the theories of deconstruction to it, in this background, how does one deconstruct dementia and the responses of caregivers?

Literature Review

Dementia is an umbrella term that refers to a number of symptoms caused by degenerative conditions affecting the brain. These conditions include; Alzheimer's (the most common form of dementia), vascular dementia (caused by a stroke), and Korsakoff's syndrome (associated with heavy alcohol use over a long period of time), (Alzheimer's Society, 2016). Dementia affects each person differently but generally symptoms include a loss of memory, disorientation and confusion, communication difficulties, and changes in temperament. A person with dementia may be able to maintain a good quality of life for a number of years after diagnosis, but generally symptoms will become more severe over time. Typically symptoms include problems with short term memory, difficulties carrying out daily tasks, loss of words, and changeable emotions. At Intermediate stage these symptoms will increase in severity and a person may also develop difficulties in recognizing people and objects, lose track of time, and experience changes in behavior. Finally, at late stage both short-term and long-term memory will suffer, a person will find it hard to follow a conversation and to recognize family member.

Most of the research work has either been done by physiological, psychological or scientific point of view. Human lives cannot be correlated to the workings of machines. The medical profession and science, looks at the human body from a faraway position, in a bid to cure the body, this usually doesn't take into account the gamut of emotions that a human goes through in dealing with the diseases.

This literature review explores the way literary representations of dementia enhance our understanding of what it is like to experience this disease, the light that dementia throw on the particular plight of the sufferer. How does knowledge, in the sense of awareness of one's cognitive decline, interact with emotional pain? Aware of the discrepancy between fictional worlds and the 'actual' world, this chapter nevertheless outlines the potential value of fiction as a means of improving one's understanding of another person's mind and another person's pain.

In the more advanced and industrialized countries of the world other than India a fair amount of research such as social impact of dementia, clinical effects of dementia and numerous scientific papers have been presented. A number of books and papers have been written on the causes, effects, impact and adaptability of dementia, but the relationship between dementia and literary fiction has taken a turn for the better and a couple of books highlighting the family trauma have also been written.

In an especially insidious disease like dementia, which brings out all kinds of emotions in a person that faces it and the family around the person, the emotional factor has to be taken into account to get a holistic understanding of how this disease operates, literature, is the most effective way to garner such an understanding.

Research Gaps Identified in the proposed field of Investigation

As has been stated before, there is a dearth of research regarding dementia in the wider context, not much scientific or social research has been undertaken to make an impact assessment of dementia in India, or in developing countries as such.

Thus there is a wide area of research with respect to dementia in the field of literature.

Additionally, even in the Indian ethos, hardly any research has been done to put the abstract theories that people researching dementia have come up with and link this research and abstract concepts to the human experience of dementia.

This is one of the important things that this paper has done, the researcher through the medium of this paper has tried to put a human face and link human experience to the abstract theories of dementia, so that this disease can be humanized to a greater degree. Any degree of abstraction without any chance to actually understand these abstractions would be a futile attempt.

Tentative Chaptalization:

Chapter 1: Introduction to Dementia

This chapter would be dedicated to move dementia literature away from the stereotypical view that dementia is solely a loss of self and showing it to be a subject deserving of diverse and varied inferences. It also would be acknowledging that in order to enable a person with dementia to retain their self they may need to be allowed to live in a different or altered reality. This chapter would be dedicated towards a more representative dementia literature by using multiple points of views to present a broader picture of the condition and by widening the focus to address the issues that go hand in hand with it.

Chapter 2: Dementia from the Perspective of Demented Person

Still Alice, written by Lisa Genova, is about a young woman's descent into dementia through early-onset Alzheimer's disease. Alice is a fifty-year-old psychology professor at Harvard when she starts experiencing moments of forgetting and confusion. But, like most busy, professional people her age would, she at first attributes these signs to normal aging, too much stress, not enough sleep, and so on. But as things get worse, as things do with this disease, she eventually sees a neurologist and learns that she has early-onset Alzheimer's.

As Alice loses her ability to rely on her own thoughts and memories, as she loses her cerebral life at Harvard, where she'd placed all her worth and identity, she is forced to search for answers to questions like "Who am I now?" and "How do I matter?" As the disease worsens and continues to steal pieces of what she'd always thought of as herself, we see her discover that she is more than what she can remember.

What the hell happened to my brain written by Kate Swaffer, will be invaluable to anyone who wishes to learn about aspects of dementia.

Life slipping away
Terrified one day soon
I won't know my children

Life slipping away
Mortified one day soon
I won't know my husband
Life slipping away
Disbelief one day soon
I won't know my family
Life slipping away
Angry one day soon
Iwon't know my friends
Humiliated one day soon
Iwon't know how to drive
Life slipping away
Despairing one day soon
Iwon't know who I am

What the hell happened to my brain is written from the perspective of truth, her own reality, part creative, part academic part non-fiction and part autobiographical in style talks about myths of dementia, the language of dementia, stigma around dementia, employment and dementia, family care partners or bubs {back up brain} prescribed disengagement et .The following lines are quoted from her article published in 'Link disability magazine'.

"Dementia is an invited visitor to my world, a welcome early 50th birthday present, one where old me seems to be rapidly moving away from new me."

The study on the effects and the ways to deal with dementia has also been studied to a great extent, questions such as quality of life of the patient, the loss of personhood of the patient, the trauma that the family goes through due to the onset of dementia in a person, the importance of memory and the link and the complexities that come with the link between dementia and old age, there is a huge amount of research on this and that is good for how dementia is bound to be holistically dealt with in the future

In *Silver Haze*, Kamla while having her first medical check-up with respect to dementia had the following feeling, in the book it has been written that:

"I felt like I was a pet dog listening to a vet expounding my medical problems to my owner."

Kamla, a typical Indian lady realizes that she has to live the rest of her life in some kind of haze finding it very difficult to look back at her own past. No moments of recall, and no peering into the future. She thinks that she has become a kind of vegetable without knowing what was happening to her.

Whereas in *My Nana is a Nutcase*, the Nana in his 80s apologizes to each of his grandkids and provides the route map to the kids and gracefully accepts his first sign of dementia by submitting himself to the care of his caregivers.

In the narrative of *Elizabeth is missing*, narrator Muad, a woman in her early 80s returns again and again to the fate of her friend Elizabeth, who she believes she suffered some violent treatment by her own son.

Chapter 3: Dementia from the Perspective of Caregivers

This has pushed dementia, the studies around it and the practical experience of the caregivers associate with a demented person to the realm of ethics, where only a few diseases have gone to. Dementia here becomes as much an ethical question as it is a biological or physiological one.

One of the first signs in Lal's (2015), Nana's progressing dementia is forgetfulness, the youngest children Dingling (Nihal) and Dumpling (Neeharika) exploit this and make sure Nana buys sweets four times for them the major ones, Avantika becomes concerned and shift their roles from dependent children to caregiver's even guardians of the old man. Ranjit Lal, in *Our Nana was a Nutcase* published in 2015 gives a really lucid description of a man who in his 80s suffers from late age dementia. The peculiar narrative of the book is such that although the children of the victim do not help in the recuperation, rehabilitation or the basic care of the patient, the generation after them, the grand children of the patient ensure that proper care is taken.

In an extreme incident that showed affection and the need for such people around the patient it can be seen that in a bid to better take care of the patient, his grandchildren kidnap the patient from their own home to save him the ignominy of being shifted into an old age nursing home.

In *Siver Haze*, written by Pankaj Varma (2014), narrates the dawn years of a typical old Indian woman who had sacrificed her own life for the needs of the family for all her years and was now suffering from a mind numbing disease. Now, in her dawn years, with the onset of this disease, she was rendered helpless in her own life. This book too describes the change in bond between the patient and the child that happens after the onset of dementia, while on the one hand the patient herself is in a semi content state due to the fact that all her physical needs and necessities are taken care of but her emotional needs aren't taken care of.

In the same vein, the son of the patient is happy in doing all that he can for his mother but he also feels a sense of loss to the extent that there is a lack of an emotional relationship between the mother and he son, because now the mother is incapable of having such a relationship due to her state.

In *Folded Earth*, written by Anuradha Roy (2011), Dewan Saheb who is leading a solitary life in Raniketh as a local eccentric without any family present around him. In the same vein as the

other books, the care isn't provided by the family due to their absence but by the villages and the servants that live around him

The focus on the above texts is the changing equations of relationships. In *Our Nana is a Nutcase*, the dependent children become care givers out of sheer affection and love for their Nana, in *Silver Haze* the caregivers get embarrassed due to paranoid nature of Kamla.

When we read *Silver Haze* by Pankaj Verma, Kamla after realizing about her disease could not help herself to eating anything, her husband her son her daughter in law, daughter, son in law, kept talking about her affliction they all were trying to work out how they would cope with her, they kept hugging and telling her that they loved her but they did not have any clue how she would cope with it even though by the evening they all had the idea as to how they would cope with her trouble.

In a small scene in *Still Alice* the three kids of Alice argue whether their mother should be trying to remember something or not, Alice asks what time they'll be going to a play the next day, he son says that she should not worry and she should not try to remember because they will not go without her. Her oldest daughter thinks that she should be exercising her memory the sort of "use it or lose it philosophy", the youngest thinks that let the mom know the information and she can do with it whatever she wants this is common in the families where there are patients of dementia, there is a disagreement and conflict. In this scene, the kids argue, hurt one another and never agree, people talk about people with dementia right in front of them as if they are not there.

In *Folded Earth* Diwan Saheb gets disillusioned of his illegitimate son Veer and his uncanny attempts to steal Nehru and Edwina's letters. The servants and friends become immediate care givers and not immediate family members. Alice a Harvard professor and researcher in *Still Alice* because of her past academic success finds very difficult to cope with demenia. Her husband John refused to watch her take her medications.

Chapter 4: Dementia and Personhood: Cultural Importance of Memory

Although, the context of this section is provided by the ethics and the value of life sections, it becomes important to actually see how dementia actually affects the personhood of the people involved in with the perils of this illness.

As a synthesis of the questions that have been put forward by the ethics section and the section involving the value of life question, this section becomes an important one to answer larger questions that are involved in the understanding of the disease, not as a standalone concept, but as a mental illness and the loss of personhood that mental illnesses beget.

This has been shown in multiple protagonists from King Lear to the Indian fiction authors.

Dementia, necessarily, is accompanied by a loss of personhood that comes with failing memory.

In both *King Lear* and *Silver Haze*, with the character Kamala, one can see that dominating characters who have controlled everything around them their entire lives, are rendered to the care of others. Intuitively, this would be a massive change for anyone to overcome, from someone who used to dictate terms in every sphere of their life, to being someone who has to be dictated to even for the execution of mundane daily activities.

Another example of this phenomenon can be seen in the book, *My Nana is a Nutcase*, in this particular book, Nana who was a caregiver his entire life is rendered to the care of his own grandsons, even for the basic needs to Nana. This would be a huge turn in anyone's life who has seen themselves as the care giver, being rendered to the total care of the family members.

Another example of this phenomenon can be seen in the character of Surat Singh, he is a highly meticulous and respected person in his community and is in a sense the leader of that community, but with the onset of dementia he too becomes totally inept at carrying out the duties that he himself had undertaken throughout his life. This too could be seen as a massive turn that would be hard to overcome.

The cultural importance of memory constitutes the reactions of the people around the patient to the loss of memory that the patient suffers, these reactions often being defined by the importance the culture around people has put on the memory of a person.

This is what makes dementia so unsettling and so jarring, it questions the idea of "personhood" itself. As an academic exercise it may be a very interesting question to answer but put in the context of a family that has to go through the disease with the patient, it becomes quite unsettling. A person afflicted with this illness is metaphorically vanishing like sand in front of the family and the society that the victim inhabits, this makes people question if this person who they have probably known for their whole life is the same person or a different person. A lifelong of memories is at stake in this equation.

Another interesting point of note is that there is a direct correlation between the age of the person and the cultural importance of memory that is affixed to that person. To exemplify, a person at 82, if losing their memory would not have problems in this sphere as it is easy to accept and culturally understood that at that age memory might start to fade, but the same thing happening to a 50 year old would be an altogether different phenomenon due to the fact that for them and for the people for them its unexpected and cultures, even small units like family that are part of society react adversely to unexpected change.

This section would be dedicated to understanding the cultural importance of memory vis a vis dementia.

Chapter 5: Humanistic Concerns

To get to the very root of any concept and how it is built block by block to what the concept essentially encapsulates, it becomes highly critical to deconstruct the concept and go to the very root of it.

Dementia, stand alone, may not be a concept as it is essentially a mental illness, but the reactions of the people that are actually effected by it can easily be put through the gauntlet of deconstruction, this would break down the concept to its core due to which, perhaps, better strategies that would take into consideration, the emotional cost of dementia could be come up with.

Alice decides that she would take overdose of sleeping pills once her disease progressed to an advanced stage. Kamala decides that she would always be nice to the caregivers and go out of the way to be gentle and polite. Dewan Saheb wanted to shut the outside doors, he dint want to be reminded of the world outside his cage. Nana, for the most part spent his days in his armchair or "Cadillac SUV" wheelchair, he is mostly silent but usually beamed happy when all his family was around him.

This section tries to deconstruct dementia in a bid to make more sense of the illness.

Chapter 6: Reality vs fiction

The chapter recognizes the embarrassing aspects of dementia and acknowledges the ways in which it challenges young people's experiences with their demented parents. These negative accounts of young people contrasts master narratives of dementia that emphasize notions of 'living well' with the condition and that the sufferer is 'still the same'. It aims at voicing inadmissible stories of young people, grappled with caregiving stress and sometimes ashamed of waiting for their own parents' death. This chapter pens down the experiences lived by the young adolescents in taking care of their demented parents or relatives. However penning down these negative experiences will be difficult for the researcher, but it would be a disservice to the research policy development and positive growth if these first hand experiences are not taken into consideration.

Chapter 7: Conclusion

The concluding section would be to synthesis the findings in the paper and come to a comprehensive understanding of what the research has entailed.

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